THE EMPOWERMENT AGENDA
Civil Society and Markets in Disability and Mental Health

Vern Hughes
Become a Member of the Institute of Public Affairs

I WOULD LIKE TO SUBSCRIBE TO THE IPA REVIEW

☐ IPA Review Subscription

OR I WOULD LIKE TO BECOME AN IPA MEMBER

☐ General Member
☐ Premier Member

I WOULD ALSO LIKE TO DONATE $ _________________

NAME _________________________________
ADDRESS ________________________________________________________________
______________________________________________________________
POSTCODE _____________
TELEPHONE ____________________________
EMAIL: __________________________________

PAYMENT

☐ Cheque attached for $ _________________
  made payable to the Institute of Public Affairs

☐ Charge my credit card $ _________________
  Bankcard ☐ Mastercard ☐
  VISA ☐ AMEX ☐

NUMBER ________________________________
EXPIRY DATE ____________________________
SECURITY CODE FOR AMEX____________
CARDHOLDER’S NAME
______________________________________________
______________________________________________
SIGNATURE ________________________________

IPA Review Subscription costs $33 annually and entitles you to the IPA Review

General Member costs $55 annually and entitles you to the IPA Review, our regular newsletter InTouch, and notice of IPA events.

Premier Member costs $209 annually and entitles you to all IPA publications (IPA Review, Current Issues, Backgrounders, Facts), notice of IPA events, plus discounts to IPA functions.

Institute of Public Affairs Ltd
(A.C.N. 008 627 727)
Head office: Level 2, 410 Collins Street, Melbourne VIC 3000.
Tel: (03) 9600 4744;
Fax: (03) 9602 4989
E-mail: ipa@ipa.org.au
Website: www.ipa.org.au
THE EMPOWERMENT AGENDA
Civil Society and Markets in Disability and Mental Health

by Vern Hughes

IPA Backgrounder 18/1, February 2006
In the last two decades, economic policy in Australia has been dramatically transformed. The importance of markets and individual choice is now understood, as is the fact that the role of government should be limited.

By contrast, the framework for social policy is basically unchanged since the 1950s. Certainly there has been the privatisation and contracting-out of some services, and in particular sectors there is greater scope for consumers to exercise their preferences. However, the basic structure for the provision of social services in health, education, and welfare remains—government decides what services are provided to recipients, how they are provided, and when they are provided. The regulation of the provision of services results in government, in effect, regulating itself.

The social policy debate in Australia is dominated by experts, lobby groups and government officials. Discussion about new directions revolves almost entirely around two themes: how much extra funding political parties are willing to promise at election time, and which level of government (federal or state) carries the blame for the problems of the system.

The users of the system, whether they are called clients, consumers, customers or individuals rarely get a say. And on the occasion when users of services do get a say, their choices are usually clear: witness for example the unabated increase in the proportion to parents choosing non-government schools.

The consequences for the community of the prevailing social policy paradigm are now becoming obvious. The answer is not more money. Without reform to the way services are delivered and without an increase in the accountability of those services, additional funding may provide no improvement at all.

Governments of all political persuasions have increased spending on social services but there's little evidence that disadvantage is being redressed. The only alternative is to find a new way of doing things and empower individuals and their families.

The reluctance of government to give up its control over social services is motivated by the belief that 'government knows best' and that individuals and families don't know what is in their own best interests. This argument is not true, and was never true. It is now becoming obvious that family and social networks, outside of the reach of government can fulfil the responsibilities once handled by government.

This IPA Backgrounder by Vern Hughes, The Empowerment Agenda: Civil Society and Markets in Disability and Mental Health, is important for a number of reasons.

Individuals with a disability or suffering mental health problems are among the most vulnerable in our community, and their welfare represents one of the primary responsibilities of society. For a variety of reasons, issues of mental health in particular are assuming greater prominence in the community. Although, at the institutional level there has been de-institutionalisation, few genuinely new policy approaches have been attempted.

Federal and state government spending on both disability and mental health continues to growth. Expenditure on disability support services and mental health is over $3 billion each annually, with spending on mental health, for example, increasing by 73% in the decade to 2003. There is no likelihood of this growth slowing.

Despite such growth there remain few outcomes measures, and it is impossible to answer the question as to whether the community and clients are receiving value-for-money. The National Mental Health Report 2005, released in December 2005, which assessed the National Mental Health Strategy revealed that after ten years of the Strategy nearly half of all state and territory mental health services did not collect or report on customer outcomes. There are few other areas of policy where such failure would be tolerated.

This Backgrounder is also timely in the context of recent calls for the federal government to take full responsibility for the provision of mental health care services.

The Institute of Public Affairs has been at the forefront of argument about reform to economic policy. The success of that argument has produced economic growth rates that are among the highest in the world and has resulted in improved living standards.

We must now begin to argue that individual and family choice and a reduced role for government should extend beyond the realms of economic management and into social policy in Australia.

This debate needs to be undertaken - not as a matter of ideology - but as a way of improving the life conditions of all Australians.

John Roskam
Executive Director
The Institute of Public Affairs
Policy recommendations

- **Consumers of disability and mental health services should be funded through a voucher arrangement.**
  
  State and federal governments should accelerate the introduction and spread of individualized funding arrangements across a range of services and programs for people with disabilities and mental illnesses and their families. Disadvantage and risk-adjusted formulae for determining individualized funding allocations are already in use in several jurisdictions in health, aged care, disability and education.

- **Federal and state funding for disability and mental health services should be pooled and distributed to individuals and families through a voucher arrangement.**
  
  State and federal governments should abandon arguments as to whether one jurisdiction or other should assume sole responsibility in disability, general health care, aged care and mental health. Where state and federal jurisdictions fund co-existent programs in these fields, funds should be progressively directed to consumer intermediaries as the entities with the capacity and incentive to integrate funding.

- **Transparent pricing should be introduced for all disability and mental health services.**
  
  State and federal governments should require transparent pricing regimes for all episodes of service or care in publicly-funded disability and mental health (places, beds, hours, courses, sessions) on a full cost-related basis so that these services may be readily accessible for purchase by consumer intermediaries.

- **Consumer intermediaries acting on behalf of clients should be funded according to outcomes and should be able to receive incentive payments for every consumer or family they enrol.**
  
  State and federal governments should introduce a payment to intermediaries for every enrolled consumer or family they attract as an incentive for new intermediary start-ups. This would assist intermediaries to acquire sophisticated brokerage, purchasing, information and financial management capacities when acting on behalf of consumers.

- **Consumer intermediaries should be able to receive a cashed-out proportion of Medicare and other programs to fund illness prevention.**
  
  State and federal governments should allow consumer intermediaries comprising people with mental illnesses to receive a capitation-based proportion of Medicare, PBS, public hospital expenditure, as well as police and justice expenditure, payable as an annual up-front payment to the intermediary for the purpose of funding a comprehensive web of illness-prevention measures. “Cashing-out” arrangements like this in Medicare are already permitted for indigenous and remote communities.

- **Government should cease funding peak bodies and advocacy groups and direct those savings to consumers and their intermediaries.**
  
  State and federal governments should withdraw public funding from peak bodies of provider organizations and re-direct these resources to the provision of incentives for intermediaries to enrol consumers. The current practice whereby governments of all persuasions fund provider peak bodies to act as sources of policy advice to themselves intensifies the already stark power imbalance between provider and consumer voice and capacity.
This IPA Backgrounder explores public policy in disability and mental health by examining civil society, markets and government, and asking what configuration of these is likely to produce the best outcomes for people with disabilities and mental illnesses.

One of the striking consequences of our bi-partisan political consensus in social policy for the past generation has been the narrowing of debate to the single question of how much public money should be thrown at social problems in the hope that they might be fixed.

Before considering alternatives it is important to recognise a number of features of the policy context in disability and mental health.

In the ten years to 2003 (the most recent year for data which are available) government spending on welfare services for people with disabilities increased from $1.7 billion to almost $3.3 billion.¹ The ageing of the population is leading to an increase in the number of people with a severe core disability - those with such a disability increased from 1.135 million Australians in 1998 to 1.244 million Australians in 2003.² The lives of nearly four million Australians are affected in some way by an impairment, or activity limitation, or a participation restriction.³

In the ten years to 2003, government funding to mental health increased by 73%.⁴ Total spending (including the government and private sectors) increased by 69% over this period to over $3 billion.⁵ In any one year, an estimated 18% of Australian adults will have experienced a mental disorder.⁶

As with all areas of social policy, how much money should be spent on disability and mental health is unknown. As was noted last year by the Commonwealth Government’s report examining ten years of the National Mental Health Strategy, it is not known how much spending on mental health services is required to meet the priority needs of the Australian population... [R]eliable international benchmarks are not available for determining what is the right level of funding to allocate to mental health.⁷

Despite the additional funds devoted to disability and mental health and the public attention to these issues, practically no progress has been made on measuring the outcomes to individuals or the community of the extra resources. The report on the National Mental Health Strategy revealed that as recently as 2000 no mental health system collected any measures of consumer outcomes, and three years later the proportion of the health system doing so was only 57%.⁸

The ‘lack of genuine and transparent data mechanisms pertaining to assessment of ongoing safety and quality of services’ was identified last year as a widespread problem in mental health in a report by the Mental Health Council of Australia.⁹

There are very few outcome indicators in the disability area. The Commonwealth State/Territory Disability Agreement makes no provision for an agreed process to collect outcomes data.¹⁰
The current paradigm of service delivery in the welfare area may be described as supply-side service delivery.

In stress-ridden state schools and over-crowded public hospitals, in welfare agencies and psychiatric care units, in nursing home dining rooms and day centres for people with intellectual disabilities, this paradigm still rules: services are dispensed to disconnected and passive clients in programmatic modules, administered by departmental ‘silos’, segmented by jurisdiction, fractured by disciplinary demarcation, and delivered by agencies that are charged with accountability, not to their consumers, but to their funders.

That both sides of politics in Australia have acquiesced in this supply-side service delivery paradigm is testimony to the strength of provider organizations in social policy fields, and the relative organisational weakness of consumers and communities. It is also evidence of the stunted development in Australia, for most of the past century, of our public discourse about civil society and social capital. Indeed there is a direct correlation between the organizational dominance of provider interests in public debate and the stunted character of our discourse on civil society.

That both sides of politics have colluded in upholding this supply-side service delivery paradigm is also testimony to a third and more recent phenomenon. Australian thinking and writing about markets has, in the past two decades, been associated almost exclusively with economists and economic matters. Markets are important, so the conventional wisdom runs, in economics, and they were particularly important in fashioning the economic reforms of the 1980s, but social policy is best left to funders and providers to sort out between themselves.

A survey by the Australian Bureau of Statistics in 2003 revealed the following:

The predominant activities for all disability groups and all age groups were visits from and to family and friends, telephone calls with family and friends, and visits to restaurants and clubs. Thus, in 2003 [the year of the survey], not only did family and friends provide most of the assistance needed by people with disabilities, they were also the main focus of these people’s social lives.

Yet the involvement of family and carers in policy development and the determination of assistance in the disability area is either non-existent or token. What participation there is by family and carers is usually only through formal system-wide processes where their influence is negligible.

More broadly, there is little recognition of the role of civil society in the areas of disability and mental health.

Civil society and markets are two critically important, but usually ignored, foundations of good social policy.

The third foundation, government, has been stretched beyond capacity in Australia for a long time. Hancock’s formulation of the problem in 1930 cannot be bettered: “Australian idealism has put too many of its eggs into the political basket”. Civil society, markets and government are the three legs—three interlocking foundations—of good social policy, but the Australian curse has been to focus excessively, often exclusively, upon just one of these—government. As our more courageous indigenous leaders now recognize, this is a recipe for social disaster.

The agenda that is outlined here is one of empowerment of persons. Civil society, markets and government are explored to determine their respective roles in shaping the capacity of persons and influencing their circumstances in ways that either empower or disempower.

If the empowerment of persons and the strengthening of their relationships is the goal of public policy in disability and mental health, then we shall need a radically new configuration of policy settings, service delivery instruments, market mechanisms and social infrastructure.

The constituencies with a mass base (health and education) naturally do better in the contest for government attention and government funding than those with a specialty base (disability and mental health). People with disabilities and mental illnesses have therefore been, and remain, the big losers from the way policy has developed in Australia. And within each social policy field, the organizational strength of providers has carried more political force than loose networks of consumers - the Australian Medical Association and the welfare delivery lobby are perennially prominent voices at budget time; family carers of the mentally ill are not.
These political dynamics have shaped social policy debate for the last 30 years. They are still present. But just as new drivers have emerged within indigenous communities to shake the foundations of past policy, so there are drivers emerging within non-indigenous Australia to shake the foundations of supply-side service delivery. These drivers are not primarily economic. They are primarily cultural and ethical in nature, and derive from the notion of empowerment of persons and the strengthening of their capacities and relationships in living the best lives they can live.

In indigenous affairs, it is now generally accepted that the social policy of the past 30 years has failed miserably. Welfare dependency, family dissolution, the erosion of personal and communal responsibility, and third world health outcomes have been its legacy. The policy settings and the service delivery mechanisms that have generated these outcomes have rightly been placed under the microscope and subjected to rigorous scrutiny.

In non-indigenous affairs, social policy remains trapped in a time-warp and has been quarantined from scrutiny for a generation. In mainstream health, education, community services, aged care, disability and mental health, a bi-partisan political consensus still coheres around the very service delivery paradigm that is now discredited in indigenous affairs.

Social policy is slowly being reshaped in the United Kingdom, Europe, and North America. Large, rules-based systems are being replaced by processes of direct funding to clients and their families.

The Blair Government in the UK has introduced ‘direct payments’ in large sections of community care, spanning home care for the aged, independent living for people with disabilities, and resources for people with mental illnesses. The Community Care Direct Payments Act (1996), administered by the same Department which oversees the National Health Service (NHS), was introduced as a direct response to the inflexibility of the NHS: ‘Direct payments create more flexibility in the provision of social services. Giving money in place of social care services means people have greater choice and control over their lives, and are able to make their own decisions about how care is delivered.’

Direct payments have also been introduced in several states and provinces in the USA and Canada, and were part of the Clinton Administration’s social policy agenda, though its capacity (in a federal system) to implement comprehensive reform in social care was more limited.

In Australia the need for a new form of service delivery, directed to the client, is slowly being recognised. In some areas, individuals are already able to tailor a service package to meet their needs. Seventeen percent of service users under the Commonwealth State/Territory Disability Agreement received some sort of individualised funding. Although ‘specialist disability services are looking to a flexible, individually focused model of service provision’, governments have been slow to respond.
It is generally agreed that the de-institutionalisation processes of the past twelve years in mental health, and the past 30 in disability, were necessary and overdue in terms of human rights. It is also now accepted that these processes were not accompanied by the rigorous development of supports and relationships in civil society that were, and remain, necessary for de-institutionalisation to work.

It is also clear that the focus on ‘rights’ obscured the magnitude of the task at hand in enabling people with disabilities and mental illnesses to live in community settings as part of mainstream life, work and play. An abstract right to live ‘in the community’ does not, by itself, generate actual social relationships and ties of the kind that constitute community.

In this sense, the notion of ‘community’ used throughout the de-institutionalisation process was conceptually inadequate in capturing the scope and magnitude of the task. It primarily implied a location (geography) rather than a set of relationships – the location was to be an ordinary street address in an ordinary suburb, rather than an institution – but with what kind of relationships? Tragically, politicians, policy makers and service providers had barely given five minutes’ thought to how civil society relationships with people with psychiatric and developmental disorders would develop – in what settings, around what interests, with which networks of people, and with what kind of nurturing and support?

Can such relationships develop spontaneously? The evidence from the past decade suggests not. Usually they require careful nurturing informed by experience and expertise. De-institutionalisation required a comprehensive nurturing of the will and capacity of family members, shopkeepers, bus drivers, hotel proprietors, sports officials and many others to form and maintain relationships with people with complex disadvantages. That is not an easy thing to do.

The term ‘civil society’ was not used during these years, but it more accurately captures the intent of the de-institutionalisation process (if not its practice), which was to shift the focus of living and support to the relationships and associations formed through interactions between people, outside formal arrangements, and in particular, outside processes controlled by officials and managers. This remains the cry, and the aspiration, of the most battle-weary disability activist – to live a life free of officials and managers. In the absence of a civil society focus upon relationships and informal interactions, de-institutionalisation simply transferred the locus of officialdom and regulation from state institutions to state-contracted managing agents with an ordinary street address.

De-institutionalisation in disability and mental health can best be understood as a process trapped in these cultural and political dynamics, and rendered incomplete as a result. As a politically ordained and manipulated process, de-institutionalisation was dependent upon social foundations and social infrastructure - between the individual and the state - which were either weak or absent. The grand asylums and infirmaries of colonial governmentalism were deconstructed when only a social vacuum awaited the former inmates. And because public opinion, on this issue and many others, was largely constructed by the political parties, bi-partisan backing for de-institutionalisation crowded out the voices, primarily of family carers, who urged caution in venturing forth into a ‘community’ that they knew in their bones was too threadbare to sustain their sons and daughters.

In-home and community-based care and supports are now surrounded by the same intrusive regulatory burden that we might once have associated with the worst of our psychiatric hospitals. In the name of risk management, a Melbourne agency providing in-home care to a woman with physical disabilities recently succeeded in dictating that the client sleep in a single bed rather than a double, since this reduced the attendant carer’s risk of bodily injury. It didn’t matter that the client preferred a double.

Making de-institutionalisation work

Victoria’s Community Residential Units (CRUs) for people with intellectual and developmental disorders have come to symbolize this problematic set of outcomes – “the institutionalisation you have when you no longer have institutionalisation”. Five people selected at random, whose conditions may range from autism to profound intellectual disability to physical disability with a mild intellectual impairment, are placed together in an ordinary house (except, that is, for the two toilets, one for staff and one for residents, the timesheets and official memos on the kitchen table, the oversized doors and restricted windows, and the signage denoting that the residents are not ordinary people). But in a building that looks like an ordinary house, the CRUs are a triumph of de-institutionalisation – except that the social interaction with neighbours and friends that the residents and families yearn for rarely eventuates.

Belatedly, there are initiatives emerging to fill the social vacuum that ought to have accompanied de-institutionalisation from the outset. In disability, initiatives vari-
ously called ‘circles of support’ or ‘planned individualized networks’ or ‘microboards’ are emerging which typically involve the creation of a circle of significant others around a person with an intellectual or developmental disability (a family member, a neighbour, a shopkeeper, a special interest colleague, a church member, a sporting club associate) who meet regularly, oversee support with daily living, and plan social interactions and relationship-formation where this does not happen naturally.\(^{25}\)

In mental health, peer-supports amongst people with mental illnesses have been slow to emerge in Australia - internationally they have a longer history in playing critical roles in overcoming social isolation, and sustaining the process of recovery.

The critical point here is that these circles of support and peer-support networks (and variations on the theme, which we may call individualized social networks) have held no place within the supply-side service delivery paradigm as we have known it for the past generation. It is only in very recent years (as initiatives celebrated as ‘novel’, ‘innovative’ and ‘creative’,) that these crucial micro-level structures have emerged and become recognized as having important roles to play. (In Western Australia, Planned Individualised Networks Inc was formed in November 2004; in Victoria the Council of Intellectual Disability Agencies conducted its first workshop on Circles of Support in July 2005.)

How is it that structural forms like these which are so pivotal to a well-functioning support system, so manifestly sensible and obvious in connecting persons with others outside official settings and arrangements, can have been absent (and not noticed) for a generation?

### The Supply-Side Service Delivery Paradigm

The set of supply-side service delivery arrangements which emerged in the 1970s and was refined in the 1980s and 1990s presented itself to governments, policy makers, service providers, advocates, people with disadvantages and their families alike, as a ‘natural’ or ‘common sense’ way in which services should be organized and delivered. In this sense, it constituted a ‘paradigm’: by ‘paradigm’ we mean a way of thinking and doing and organizing that is hegemonic in a particular time and place, with a guiding rationality that assigns both an over-arching logic to its operation and an a priori explanation for its deficiencies.

The structure of this paradigm was quite straightforward, and came to be summed up in the notion of the ‘purchaser/provider split’. In this split of functions, the supply-side funder (government) is simultaneously the purchaser, buying the provision of services to a range of client groups on a contract basis in accordance with the funder’s preferred policy priorities. Providers, being contracted to the funder/purchaser, are held accountable to the purchaser, not to their clients. Contracts are terminated or renewed by the purchaser, not by the client. The delivery of services is typically discipline- or function-based, corresponding to the departmental structures or ‘silos’ of government rather than the configuration of needs embodied in presenting clients.

This paradigm emerged in the 1970s as part of a world-wide expansion of the public sector under the intellectual leadership and direction of the social movements of the New Left.

There were three factors which coincided in shaping the formation of the paradigm.

- First, there was an ideological trend, also global in its dimensions, towards the absorption of voluntary, charitable and mutual forms of social support and provision into the publicly-funded sector.
- Second, there was a trend towards the professionalisation and corporatisation of charitable and community-based forms of social support and the creation of a field of activity that came to be known as ‘human services’.
- Third, there was an explosion of activism from disadvantaged groups for more and better services. Activists and the new crop of human services providers found they had a common interest in a rapid expansion of service provision. Many formerly voluntary and charitable bodies found it easier to seek and obtain public grants for their operations and to tailor their mission to the delivery of government contracts, than to continue with previous forms of operation. And with ideological currents favouring state funding of social provision, a push-pull dynamic forged a model of service delivery in human services that seemed to meet the needs of its various stakeholders.

Because this emerging service system traversed a wide variety of fields including health, welfare, employment and training, housing, education, child and family services, aged care, child care, and youth services, it soon came to be constituted through a plethora of contracted providers. With a proliferation of service and program types, built around new disciplines and new client groups, this service system was soon characterised by a bewildering complexity, with deep information and power asymmetries between the consumer or user and the service provider.
'Advocacy' emerged as a means of connecting persons with this complex service system.

On the assumption that the service system existed prior to and independently of, persons, advocates were needed to assist people with disadvantages to access its benefits. Publicly funded advocacy thus came to be an integral part of the paradigm. And advocacy and delivery functions frequently came to co-exist as distinct operational units within the same service provider.

'Activism' within this paradigm assumed a particular set of functions. It cohered around the procurement of rights-based procedural entitlements for clients. That is, no matter how difficult it might be to navigate the service system and find integrated care for a person with complex needs, that person still had a 'right to complain' and channels for the expression of grievances.

Consumer 'representation' in management was sought as a means of improving the 'fit' between the individual and the service system. And in the absence of market mechanisms to allow for the expression of consumer voice and consumer preferences, activists sought more and more differentiation in supply-side delivery to client types by gender, ethnicity, and disadvantage classification. This came to mean still more fragmentation in the service system, driven by an assumption held by activists, providers and governments alike, that more and more service delivery meant better services for increasingly diverse client groups.

In fact it came to mean more fragmentation, less likelihood of integrated care, and greater difficulty for governments in monitoring outcomes across provider, program and disciplinary boundaries.

'Community development' emerged in this context. It was a response to the passivity generated by the supply-side paradigm and an attempt to recover a spatial dimension in human community outside the supply-side delivery of services. It was, however, largely shaped by the paradigm in that it framed its purposes around the practices of advocacy and activism, seeking to orient service delivery towards the filling of gaps or supplementing these gaps with additional forms of activity. In this sense, 'community development' in the 1970s and 1980s emerged as a supplement to the supply-side service delivery paradigm - at no stage did it typically anticipate breaking down or supplanting that paradigm.

'Passive welfare' can be understood initially as an indirect consequence of the operational dynamics of the supply-side system, but in its mature phase, client passivity can be identified as the principal legacy of the supply-side system. In indigenous communities, there is a now a widespread acceptance of the Pearson thesis that the condition of passive welfare has been generated by the very service delivery system intended to 'help' indigenous Australians. This insight is equally applicable (but has yet to be equally recognised) in white communities of people with multiple disadvantages including family dysfunction, long term unemployment, mental illness, homelessness, substance and gambling addictions, and engagement with the criminal justice system. The ethic of personal responsibility and mutual obligation required for recovery and rehabilitation in these areas is incompatible with the phenomenon of client passivity generated by the service system. Belated recognition of this dynamic is now one of the factors driving the paradigm's deconstruction.

A reconsideration of the nature of 'risk' is another. Supply-side service delivery systems were highly risk-averse – uncertainty in outcomes was eschewed and rigorous control mechanisms were put in place to accompany the dispensation of 'help'. The trouble is, taking risks is an essential part of life. It is certainly an essential part of learning to live independently. Risk-aversion and passivity go hand in hand, and supply-side service systems encouraged both.

In 2006, the supply-side service delivery paradigm is beginning to fade because its alliance of stakeholders no longer share a common stake in its continuation. Governments are unable to monitor cross-disciplinary or cross-departmental outcomes in a context of bewildering program complexity. Service providers trying to tailor programs to individual needs are faced with insurmountable operational difficulties when phenomena of disadvantage show scant regard to program and disciplinary boundaries. Consumers have discovered that service responsiveness is not guaranteed by unlimited differentiation in provider types by cultural group or gender. Dependence, not individual capacity, is fortified by complexity and fragmentation. A person's relationships and community interactions cannot fit into supply-side frameworks.
An example of community empowerment

**Person by Person** is an initiative of several families of children and young adults with varying disabilities in the eastern suburbs of Melbourne. Sick of standardized services for their dependents in the late 1990s, these families explored ways of employing resources that would work better for their sons and daughters and simultaneously enhance their own capacity to parent persons with complex disadvantages and nurture the best outcomes possible for them. Their grass-roots innovation embodies the key features of an emerging new paradigm in social policy.

As a group of families whose sons and daughters were participants in day centres and other training programs for people with disabilities, these families successfully negotiated with the Victorian Department of Human Services to have the dollar value of their services quantified, and this amount transferred to and administered by a financial intermediary or budget-holder of their choice, on the understanding that the group of families could then select and appoint a support co-ordinator for their sons and daughters. The support co-ordinator was then given a brief to purchase a mix of services chosen by each family (which may be education, home help, day care, respite care, singing lessons) with the budget-holder administering the financial allocations and acting as the employer on behalf of the family. Each family selects its preferred staff (carers, drivers, cleaners, singing teachers).

This model is known as ‘family governance’. Following its establishment in 2001, several variations on the **Person by Person** innovation have since been established in Victoria, Tasmania and Queensland, with families exercising either individual or group management of allocated support funds. Families in Partnership was formed in Victoria in 2004 to facilitate these practices on a larger scale. In all of these cases, a consumer-directed flow of resources has been undertaken to enable families (individually or in small groups) to assume responsibility for creating a solution to a problem that is well known to them, namely, how to personalize the lifestyle arrangements for their family members rather than live as passive clients of providers and bureaucrats.

Similar arrangements for a consumer-directed allocation of support packages have been introduced in accident compensation and aged care fields, as well as disability, in several jurisdictions, and the South Australian Government is about to introduce an individual funding package of this kind in mental health. Most of these arrangements still assign the support package in the first instance to an approved agency, with the agency assuming brokerage functions on behalf of its clients. In some cases, consumers are permitted to transfer from one broker to another from an approved list, but in few cases are the consumers permitted to appoint a financial intermediary of their choice and in none are they permitted to collectively constitute an intermediary for their various purposes. The significance of the **Person by Person** initiative is that it established a precedent for consumers (in this case, families) to negotiate with a government department for a quantifiable allocation of funds to be transferred to a consumer-directed destination on terms determined, not by an established program, but by an entity of consumers.

The genie is now out of the bottle. Having determined a consumer-directed destination for one category of support funds, these families now seek a redirection of payments from another funding program in Victoria, Futures for Young Adults, so that training funds may be held by themselves to purchase the training services they prefer, rather than paid to TAFE colleges and other providers. Funding for TAFE training for people with disabilities has previously been paid directly to TAFE colleges who, in another case of “the institutionalisation you have when you no longer have institutionalisation”, use the payments to combine a group of people with disabilities in a single classroom, employ one tutor to keep them occupied, and deliver a standardized training module which may or may not meet the needs of the individuals concerned. Disaggregating the funding by enabling individualized family purchases of training services is not in the interests of the TAFE institutions, but is indisputably in the interests of the individuals requiring individualized training options.

Once consumers experience personalized supports and individualized purchasing, there is no going back to the Soviet-style methods of mass dispensation. Consumers and their families have a limitless range of preferences in respite care – a consumer-directed payment to make these purchases has a greater prospect of matching these preferences than an allocation of places to providers. Families have a limitless range of preferences in child care. Parents have a limitless range of preferences in educational supports in schools for children with disabilities, learning and behavioural difficulties. Person by Person is a methodology, not simply the name of a group.
Grass-roots initiatives have emerged because cracks have opened up in the supply-side service delivery paradigm. Initiatives have developed which display in embryonic form the key features of person-centred supports and consumer-centred systems.

To universalise these features in public policy, eight structural innovations are required:

1) System-wide intermediaries between consumer and provider.
2) System-wide recognition of individualised social networks.
3) Consolidated person-centred consumer-held information systems.
4) Individualised funding packages across service and program types.
5) Transparent pricing mechanisms for services.
6) Competition between consumer intermediaries.
7) Competition between providers.
8) Long-term financial asset development.

Consumer intermediaries are needed to enable people with disabilities and their families to choose and purchase (individually or collectively) their preferred supports. Agents or brokers like this operate in almost all other industries — insurance, finance, real estate, the law, agriculture — where information asymmetries limit the capacity of a purchaser to know all that there is to know. Only recently have we witnessed the introduction of brokerage arrangements in disability.

There need be no prescribed structural form for consumer intermediaries: the function may be performed by a not-for-profit community organisation, a for-profit financial agent, a health fund, a mutual trust formed by people with disabilities or their families - indeed any entity with a capacity to aggregate consumer enrolments, manage their financial entitlements and enter contractual arrangements on their behalf, and manage consumer purchases to the mutual satisfaction of the intermediary and consumer. Intermediaries should be free to contract with providers in developing price and service quality arrangements of benefit to their consumers and to develop packages of care, innovations in information management, and ancillary benefits for their pool of consumers as they see fit.

The consumer, however, must retain the freedom to select the intermediary of their choice (and to collectively form one if they wish) or to freely transfer from one to another.

Consumer intermediaries of this kind are already a recognised part of the service system in some states, exercising brokerage and (sometimes) case management functions in in-home supports, respite care and training. The market-based leverage of intermediaries is proportionate to the scope of services that they are permitted to purchase across jurisdiction and service type – the greater the scope for purchasing, the greater the market leverage. It is essential, however, that intermediaries are independent of providers – many large service providers in disability presently combine brokerage and provision functions. These functions should be disaggregated.

In the old paradigm, information about the service system was accessed through the providers. In the new, information dissemination is channelled through intermediaries, independent of providers. As sources of comparative price and service quality data, intermediaries enable market-based regulation of price and service quality to emerge in response to their purchasing power.

Constructing a diverse range of consumer intermediaries with varying philosophies of care and enhanced operational sophistication is an important task that is not dependent on prior public policy change from above. It is dependent on entrepreneurial initiative from below, though governments may provide incentives for their development.

Where a group of family-members, neighbours and friends meet and plan social support and interactions around a person with a developmental or psychiatric disability, these interventions typically provide the foundations for that person’s social world. But these efforts presently remain external to the delivery channels through which daily living, educational, employment and training, recreational and income supports are accessed.

One method of instituting system-wide recognition of these individualised social networks is to assign them some of the case management and co-ordination functions required by consumer intermediaries (where the consumer is incapable of acting in this capacity unaided), or to assign them a role in the acquisition of these functions.

Individualised funding packages should include an allocation to resource these co-ordination functions. This expenditure is already contained in the existing service system, but it is locked away in block funding allocations to
institutions and delivery agencies, and quarantined from consumer scrutiny and direction. In particular, there is no mechanism in the current supply-side system for consumers and families to select and appoint their co-ordinators, or to terminate their appointment in the event of poor performance.

3) Consolidated person-centred consumer-held information systems

Person-centred information systems containing a consolidated record of consumer history, interventions, supports and care plans that are transferable across provider, program and disciplinary boundaries are essential. Currently, this information resides in the filing cabinets or computers of every speech therapist, psychologist, general practitioner, teacher or case manager who in engaged in one professional episode or other of a person’s life. There it remains, as consumers undertake multiple assessments at each point of entry to each component of the supply-side system.

Intermediaries would serve as the natural entity in the support system for the introduction of a much-needed consolidated record. No private or public provider group has, for the past century, had any financial or other incentive to produce a consolidated information system that is transferable across service types with the aim of integrating various interventions and care strategies and enhancing outcome monitoring. As a result, no information system of this kind exists. Various Australian governments are now exploring the introduction of electronic records in general health care, but they have stalled on the key issue of what incentives might entice disparate practitioners and consumers to actually use them.

The only solution to this impasse is to introduce market-based incentives which link use of a consolidated record with contractual arrangements between consumer intermediaries and providers. Systems which are consumer-held, and vest ownership in the consumer’s intermediary rather than in the provider are the only means of overcoming the otherwise insurmountable legal and financial obstacles to information integration.

4) Individualised funding packages across service and program types

The introduction of individualised funding packages across a variety of categories of client need in aged care and housing support, as well as disability, has admitted the precedent of allocating resources to persons. Policy reform now requires a major extension of this format to encompass every aspect of disability support funding, and the integration of disparate packages across service and program types.

The Program for Students with Disabilities in the Victorian Department of Education and Training is a case of a funding program which remains outside the trend of individualised packaging, which attracts deep and abiding parental hostility. Students with a disability or impairment who require assistance to learn in a mainstream classroom are assessed on the basis of an Educational Needs Questionnaire and, if eligible, are assigned funding at one of six levels ranging from $4,000 to $30,500 per year. This money is payable to the school to be used for student assistance (primarily in the form of an employed integration aide attached to the student for whom the funding has been made available). Educational goals are then set for each student, which, in theory, require both parental and school support.

In reality, schools employ integration aides and other supports to meet a range of school priorities, and it is commonplace for aides to perform a range of duties for a range of students. Whether schools divulge the dollar value of their funding to parents, the hours of integration aide time and their required duties, are matters for school discretion. Many parents hold the view that sporting equipment, excursions and arts programs are often resourced from allocations ostensibly attached to their child. Whether they are right or not in this suspicion is less important than the fact of their denial of full financial information about the employment of funds allocated to their son or daughter.

Since an increasing number of funding packages are now payable to consumer brokers with the aim of enabling choice in supports, the Program for Students with Disabilities could readily allocate its payments to agents of parents (rather than schools) so they can purchase (individually or collectively) the learning supports they prefer for their child in achieving their individual educational goals. A consumer intermediary like the Families in Partnership entity in Melbourne would be required to assume the financial management and employment functions on behalf of parents.

It should also be possible for these funds to be employed in private schools, or for parents to pool their funds to establish a school of their choice. That the Victorian Department of Education and Training remains vehemently opposed to these individualised funding methods, whilst their colleagues in other departments are increasingly embracing them, is indicative of a paradigm in process of decay, where its cracks appear unevenly.

The point is that the precedent and methodology of individualised funding packages is now established. Where a person with a disability is in receipt of several packages (one for in-home support, one for school support, one for respite care), these should be consolidated not only to
streamline operations but to integrate a person’s supports so as to maximise their effectiveness.

5) Transparent pricing mechanisms for services

Individualised funding arrangements in turn require an ability to purchase a wide variety of services and supports with transparent pricing. All publicly funded services should be required to develop pricing regimes for episodes of service or care offered to the public (places, beds, hours, courses, sessions) on a full cost-related basis easily accessible by consumer intermediaries. Although some steps towards this system of pricing are under way, a rapid acceleration of this process is required. While the market purchasing power of intermediaries will provide an incentive for institutions and agencies to make this change, a legislative requirement to this effect may also be required.

6) Competition between consumer intermediaries

The development of competing consumer intermediaries is the key requirement for enhanced competition and a functioning market in disability supports. A mix of financial incentives and regulatory reform will be required, for an initial period at least, to encourage the development of intermediaries which are able to bid aggressively for the allegiance of consumers. State and/or Commonwealth governments could introduce a fee payable to intermediaries for every enrolled consumer or family they attract as an incentive towards new intermediary start-ups. Regulatory reform that streamlines the multiple layers of reporting requirements for existing brokers would also be required.

7) Competition between providers

The purpose of introducing enhanced competition amongst providers of disability services is not to commercialise these organizations or to force them to embrace every fashionable management trend. That process happened during the heyday (the last ten years) of supply-side service delivery, as agencies competed with each other vigorously to win government contracts.

The purpose of introducing enhanced competition amongst providers is to get them to bid vigorously for the allegiance of consumers and their intermediaries. Accountability to the consumer through their intermediaries is an entirely different business from accountability to governments. This kind of accountability is best achieved not through regulation but through an enhancement of the market power of consumers through mechanisms of aggregated demand and brokered purchasing. For these mechanisms to work, they must be independent of both governments and providers—and that, conceptually and organisationally, is a radical point of departure from the old paradigm.

8) Long-term financial asset development

How can people with disabilities acquire financial assets for their security in later life? Tragically, this was not a question asked during the supply-side ascendancy. It was assumed that people with disabilities would be perennially welfare-dependent, living from hand to mouth, week by week. Superannuation, home ownership, and an investment portfolio were aspirations other people were entitled to hold, but not people with disabilities.

It is now recognised that life-long financial assets can be generated by and for people with complex disadvantages through a variety of special policy instruments and private mechanisms. Part of the life-long financial allocation to a person with a severe disability can be invested in the early years of a person’s life in expectation of substantial returns in later years. This requires a degree of long-term planning and investment that was not possible in an environment defined by a short-term dispensation of services.

It also requires an engagement by financial services and property management businesses as partners and investors in the field of disability, not simply as donors to service suppliers. That, too, is a point of departure from the old paradigm.
Policy Design - Mental Health

These eight structural innovations in disability are equally essential in mental health if we are to develop person-centred supports and consumer-centred systems.28 The rationale for the reform of the mental health agenda differs from that in disability in three respects.

1) A focus on prevention and treatment

First, mental health reform should be primarily oriented to prevention and treatment of illness, rather than the development of life-long supports. There are, of course, life-long mental disorders that require the same life-long planning and support arrangements as in disability, but the emphasis on prevention and early treatment of mental illness to avoid long-term incapacity intensifies the imperative for person-centred rather than institution-centred arrangements. The mental health system is full of individuals with serious mental illnesses which could have been ameliorated or treated more adequately had earlier interventions taken place. In this circumstance, the inability to connect individuals adequately with the means for early and preventative interventions has been, and remains, a principal systemic failing of the current service system.

This implies a particularly important role for individualised social networks in mental health, particularly those with a peer-support character, in breaking the conditions of isolation which conspire against early treatment and prevention. Italy has a highly developed network of peer-support organizations run by and for people with mental illnesses (structured usually as co-operatives and run on enterprise models) which provide a wide range of supports, employment, housing and other activities. Our service system lacks this kind of mutual entity, which should have been put in place as an accompaniment to the de-institutionalisation process. It wasn’t put in place in the 1990s, because our service delivery tradition has been, and remains, oriented to dispensing services only when those with an illness get around to presenting themselves to a dispensing service.

2) Access to cashed-out benefits

Second, the entanglement of mental health services with the general health system means that a large proportion of the resources made available to general health care are locked up in that system, and are unavailable for preventative supports and treatments for people with a mental illness. Because the general health system is incapable of releasing resources for prevention, people with mental illnesses are unable to access their Medicare contribution and their share of Pharmaceutical Benefit Scheme (PBS) expenditure for preventative supports.

Mental health consumers should be permitted to have their share of Medicare and PBS expenditure paid directly to the intermediary of their choice.29 Consumers who elect to register in this way with an intermediary should also be able to receive a cashed-out share of Commonwealth and state expenditure on public hospitals (adjusted for health risk) payable to their intermediary.30 This would mean that consumer intermediaries comprising people with mental illnesses would be able to receive a capitation-based proportion of Medicare, PBS and public hospital expenditure payable as an annual up-front payment to the intermediary for the purpose of funding a comprehensive web of preventative measures.

3) Pooling of resources

Finally, the entanglement of large numbers of people with mental illnesses with the welfare, housing, police and justice systems means that illness prevention and social supports have to be integrated in ways that can only be done effectively if they are individualized and person-centred, and pool resources from a variety of funding streams. Since it is now estimated that between 30 and 40% of the prison population are people with mental illnesses, allocations from police and justice budgets to intermediaries for preventative investments might also be considered. Pooled packages of direct funding for individuals from several funding programs are our best antidote to the fracturing of the service system (psychiatric interventions, housing, social support, employment and training, justice) because they allow forenterprising and integrated uses of these funds.
A new policy framework

It should now be clear that the structure of this emerging new paradigm in social policy entails a shift from the provider/purchaser split to a three-way *funder/provider/purchaser* split, where the purchaser is not the government but the consumer and their family, through their intermediary. By distinguishing the purchasing function from the funding function, consumer responsiveness and accountability are served through market mechanisms rather than consultative and advocacy mechanisms, with demand aggregation and brokerage arrangements enhancing the consumer’s market power.

There is, nevertheless, a huge deficit in infrastructure development on the demand-side in the human services that will require attention before the emerging paradigm can supplant the old. Entrepreneurial initiatives in the form of new start-up intermediary ventures, with capital-intensive information systems, will be required.

The role of government remains important. Its business is to facilitate institutional redesign for the empowerment of individuals and families. In the new paradigm of empowerment, government is a funder not a purchaser, a regulator not a manager.

The obstacles, however, remain formidable. There is a residual managerial culture in government and service providers, an oppositional culture amongst advocacy organisations who see consumer empowerment as leading to their redundancy, and a strongly paternalistic culture amongst politicians, who must, it seems, always be seen to be delivering a service (whether it is effective or not) for one or other group of voters.

Funding the Consumer - Other Applications

It is no coincidence that the first significant cracks in the supply-side service delivery framework have emerged in disability. This can be attributed to the highly personal nature of the supports required by people with disabilities, and the high degree of personal sensitivity at stake in how these methods are chosen and put in place.31 ‘Person-centredness’ has therefore emerged in the disability fields as an ethic to be employed in assessing service delivery systems, funding arrangements, and decision-making processes.

But having emerged first in disability, it is clear that demand-side person-centred service acquisition frameworks will spread throughout the social services.

Aged care service provision already includes several programs with individualized funding packages. As an ageing population searches for ways of supporting itself with flexibility and individuality, direct funding mechanisms to persons rather than institutions will fit the instincts of ageing baby boomers.

The Minister for Ageing has recently suggested the following model for ‘consumer-driven aged care’ in Australia.

Options could be developed where public and private dollars follow the person rather than the provider. A person needing care could, with advice from families and professionals, decide how to spend the dollars earmarked for their long term care. Care could be purchased from the sources they choose. For example, a spouse, relative or friend could be employed as a personal care assistant.

In Austria, older people are allocated a personal budget to purchase services from competing agencies, to employ a care assistant, purchase physical aides or undertake home modifications.

Aged care in Germany includes an individualised care payment, which people cash in at a residential care home of their choice, or receive a variety of vouchers for particular needs, such as nursing, personal care or supported accommodation.

Such options would need to include adequate safeguards to ensure that personal choice is enhanced and quality care delivered. Also, in situations where older people, or their families, will not or can not take greater control over the exercise of that choice, there could be a role for intermediaries or case managers.

As the Boomers become the ‘new old’, they are likely to be more active consumers and demand greater control of their aged care, as they have most other matters over the past five dec-
ades. They are likely to derive greater satisfaction from the independence, control and choice offered by consumer-directed care.\footnote{32}

In the care of people with chronic illnesses, and the management of their conditions, the same framework of person-centred supports is required. Since chronic illness management constitutes the bulk of health expenditure, health policy reform will need to employ the same structural features outlined here, though the political opponents of consumer-centred systems in health care remain far more potent than those in disability, mental health and aged care.

Individualised funding packages in schools are essential for students with learning, behavioural and social difficulties, as well as disabilities. Parent advocates for this funding mechanism are emerging in all states. And since individualized learning for all students is an accepted educational goal, an adjustment of funding processes to match the educational processes will eventually take place, though the teacher unions, like the AMA, will go to the barricades to prevent this shift taking place.
The Process of De-Institutionalisation in Disability

The process of de-institutionalisation in disability emerged formalised the emphasis on individual self-determination, choice, participation, and citizenship.

Acknowledged in *Not For Service*.


The concept is best outlined in Etmanski on behalf of the Canadian organisation Planned Lifetime Advocacy Network.


The process of ‘cashing-out’ Medicare and PBS payments is already undertaken in remote Aboriginal communities by the Australian Government Department of Health and Ageing as a means of allocating health resources to these communities.


While these cracks have emerged first in disability, they have nevertheless required a decade of gestation. See *Competition and Brokerage*, A. Grieg (Paper presented to the Conference: Brokerage—Empowerment or Bureaucracy? After Care Association of New South Wales, 1992); *Individualised Funding and Service Brokerage: A Model for De-institutionalisation* (Unpublished paper, 1990).

The Institute of Public Affairs

The Institute of Public Affairs is an independent, non-profit public policy think tank, dedicated to preserving and strengthening the foundations of economic and political freedom.

Founded in 1943, the Institute has an exceptional reputation as the leading Australian political think-tank, and remains at the forefront of the political process, defining the contemporary political landscape.

About the Author

Vern Hughes is Executive Director of Social Enterprise Partnerships, a Melbourne-based development agency for innovative community ventures. He is formerly Executive Officer of South Kingsville Health Services Co-operative Ltd, a consumer-owned non-government primary health care organisation in Melbourne’s west.

The views expressed in this publication are those of the author and do not necessarily reflect the views of the Institute of Public Affairs.